SUMMARY OF ISSUES RAISED AT 36 COMMUNITY-SPONSORED OLMSTEAD FORUMS:

September 2002 to January 2003

California Health and Human Services Agency

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Public forums were hosted by many public and private organizations and agencies throughout California from September 2002 to January 2003. The purpose of the forums was to identify issues that people consider important to address in the California Olmstead Plan.

The forums were sponsored by over 68 public agencies and community organizations representing older adults and people with psychiatric, developmental and physical disabilities. More than 600 people (over one-third of them consumers or family members) participated in the 36 forums for which reports were sent to CHHS. Participants were people who use services, family members and friends, providers, caregivers, public officials and advocates.

The forums were primarily conducted as roundtable discussions or public hearings. In some cases, they were conducted in survey form to increase input from people receiving services, or by telephone and email to reach more people in rural areas. Below are the issues raised most frequently at the forums for which CHHS

received reports. A copy of the report form and a partial list of forum sponsors are attached to the end of this report.

Overarching themes of dignity, respect and choice:

People want to live with dignity and be treated with respect. They want to live/remain in their own community. People indicated that they want more freedom, control and choice in their lives. People indicated they want choices in:

Where they live

The staff that work with them

The food they eat

Who their roommate is

What they buy

Making lifelong decisions

At one forum it was suggested to use the "self-determination" model

KEY ISSUE I: Consumer Preferences

A. What services & supports do consumers want most?

The participants at the forums focused on several areas relating to consumer preferences. In general they cited the need for

-People to have a choice

-Individualized supports and services

-Better access, and more, services, housing, and transportation

-Longer hours of services and transportation

-Quicker response time for getting services and transportation

-More information on available services, in several languages

-One stop shopping for services

-Access to services such as IHSS for people who don't meet the qualifications

Comprehensive Transition Services:

"People want training and assistance that

increase flexibility" and "give wings".

It is important to provide the community and people needing/using services adequate information about what is available. Specific suggestions were to:

-Provide more information in different languages

-Provide education to understand Home and Community Based Services (HCBS)

-Develop 1-stop community treatment, service and education center

-Provide links to services, e.g. community liaisons to assist people to access services (e.g., ÇalOptima)

-Develop caregiver resource center

Funding & Resources should follow the consumer; shift funding from institutions to the community; Medi-Cal based on disability, not income; coordinate funding of SSI & IHSS so monies are available to person on discharge; assure housing vouchers to people as they come from institution

Skills training is a critical part of the transition process. Specific training could include life skills, time management, self advocacy, how to train staff, develop healthy relationships, setting personal boundaries, community access, anger management, medication awareness, sex education.

It was proposed that disabled people share their successes, incorporate peer support and learning.

Crisis intervention is critical during the transition process. People need access to crisis services 24/7 during this period in order to get help to keep them in the community.

Address specific issues for people that leave the Developmental Center to go to community, the community does not provide the same services as the DC, the transfer is difficult and aging parents are concerned about the care of their children as they are no longer able to provide support

Range of Need Services:

Housing: Almost all of the forums addressed the need for affordable, accessible housing, including home ownership or mobile homes,

with supports. Many people indicated the desire to remain living in their own community. Specific issues were:

-Housing for parents living with adult children with disabilities

-Supportive housing options, including on site supports

-Supports could include house cleaning, cooking, home health, live in staff (with own room)

-Need handy person for minor home and appliance repairs

-Home modification and repair

-More Section 8 vouchers; money to rent shared apartment

-Accessible laundry facilities

-Close to shopping (food and clothes)

Transportation: Over two-thirds of the forums addressed the need for more affordable, accessible transportation, including the need for better routes and transportation across public jurisdictions – needed services are not always within a jurisdiction, door-to-door para transit for

non medical emergences, to get to social activities and programs, evening hours

Employment and Education: At lest half of the forums addressed the need for educational opportunities, job training and employment with living wage. People expressed the need for special education, computer training, access to neighborhood schools, Apprenticeships and internships leading to real careers (not just maintenance & gardening), Meaningful work, employment support and assistance; use of buddy system

Medically-related services: People identified affordable medications, better medical care and stabilization, dental services, affordable meds, home-delivered medications, in-home psychiatric counseling, 24/7 emergency attendant care (e.g., Easy Does It, Berkeley), durable medical services; medic-alert bracelets, long term care insurance

Food: There was a range of food services identified:

-Home-delivered meals

-Home-delivered meals for younger disabled population

-Congregate meals

-Good food banks

-Faster access to food

-Grocery delivery services

Mental Health Services: Specifically mentioned were services for people with a dual or triple diagnosis of mental health and developmental disabilities, mental health, developmental disabilities and deafness.

Other services identified include Independent Living Centers, consumer support groups, senior centers, adult day care, Lifeline, hospice, respite care, reader service, homeless shelters, free computer access, day activities and day treatment, friendly visitor, programs that tap in to people's creativity, interests and talents; recreation services for child/teen and young adults; outings and trips; social activities to reduce isolation – including evening and weekends

People in institutions or residential facilities want more off-unit activities, good quality food and to be able to keep pets

Staffing:

Participants identified several staffing issues to address, including having staff that mirror the diversity of the community, multilingual and multicultural staffing and services, staff trained in American sign language, continuity of care with the same doctors and treating professionals over time, staff who listen and are knowledgeable about the person's particular disability, 1:1 staffing, care takers that can help with transportation, care, shopping and medications, Participants also addressed the need for better wages and benefits for staff and caregiver retreats

B. How do consumers think services should be delivered?

Services need to be in the community, respectful, consumer-friendly, individualized, accessible and affordable. Variety and choices are important. Information about services needs to be available. Services should be coordinated, especially federal waiver and county (IHSS) programs – different rules for different funding streams are challenging for people to manage. Specific suggestions included

Door-to-door

Vouchers

In-Home

One stop shopping

By one provider

Have a coach/manager

Hire consumers to do outreach and be peer counselors

Develop sliding scale for people not eligible under Medi-Cal that need the services

c. Who should be responsible for service delivery?

Participants identified current providers and funding sources as the parties to be responsible for service delivery: state, county, cities, for profits and non-profits, transportation companies, regional centers. Organizational suggestions ranged from a single agency to assist person in accessing all services to multiple government agencies working in collaboration with community partners with cross training

D. What existing service systems can be modified to meet need?

Several suggestions include: IHSS needs better infrastructure and resources; increase number of allowable IHSS hours; eliminate banked case system; assisted living should be covered by Medi-Cal; more flexible use of funding; flexible hours for health care aides and nurses, not just 4-hour blocks; use expertise of Developmental Centers in the community; increase access to affordable housing; modify housing models to develop group living situation, "frat" houses, that aren't restrictive as licensed facilities; give tax credits to landlords that accept Section 8; agencies that serve one disability should expand to serve broader range of disabilities; expand Rehabilitation to include Community Re-Integration training; develop attendant registry; training IHSS aids; expand 1915 waivers to full extent federal rules allow; modify existing transportation system; need speedier services at Regional Centers; more of everything

E. What new services are needed and who should develop them?

"Develop a robot to perform heavy housework

to make up for the lack of aides!"

New services need to be developed from the perspective of the consumer, involve them in the planning. Specific suggestions include: doctors on wheels, implement Ticket to Work; consumer union, ASL interpreters on standby where deaf and hard of hearing are likely to be, support services for people who don't yet need full care; mandatory behavioral specialist; help people start their own business; mobile rural adult day care; services for non Medi-Cal eligible people.

KEY ISSUE II: COMMUNITY NEEDS/BARRIERS

A. What key services and supports need to be expanded?

Participants at all forums identified many of the same services/supports that need to be expanded:

Services	Funding & Staff
IHSS	Information and

	referral
24/7 attendant services	Medicare HMO's
Better coordination of transportation regarding bus routes, especially across jurisdictions	Services for people not eligible for Medi-Cal
Adaptive/assistive technology/equipment	Financial resources and support at a state level/redirect $ to community
Services for people with mental & developmental disabilities	Culturally competent, multilingual staff
Medical care	Medi-Cal waivers
Attendant care	Increase salaries
Case management	Increase advocacy training
Affordable	

housing/housing subsidies	
More in-home services	Education of public officials and community to reduce NIMBY
Respite care	
Medicine/drug prescriptions	
Mental health for older adults	
Meals on wheels in more communities	
Employment	
Affordable legal assistance	

B. What are barriers to growth of these services?

The forums focused on limited funding and resources, lack of information, lack of education, lack of coordination and inadequate land use

planning all contribute to the barriers to growth of these services. As examples:

Limited funding & resources: No Medicare HMO in rural community; lack of affordable housing; fragmented services; little flexibility in funding; high bureaucracy/low reimbursement levels; lack of qualified personnel; inadequate insurance coverage

Lack of information: People eligible for services don't know about them

Lack of education: Community resistance to programs and housing – no knowledge of people with psychiatric disabilities (including law enforcement); lack of staff training related to strengths-based assessment and planning, lack of knowledge about community living and resources

Lack of coordination: Lack of consumer input, service coordination, agencies fail to collaborate

Lack of Enforcement: Local transportation companies not providing ADA para transit as required for fixed route bus systems

Inadequate land use planning: No planning related to growing senior population

C. Who are the key community players that could help?

Everybody!

Participants identified a large range of positions and agencies/organizations that could help resolve issues including: Legislators; Federal, State, Regional County, City government departments; housing and transportation authorities; regional centers; disability services providers; businesses (realtors, housing developers, media) service organizations; schools; advisory board/councils; insurance companies

D. What community strategies could help to expand services?

Develop "out of the box thinking"

Participants recommended many variations of coalitions and collaborations that could help maximize services: Collaborations among agencies at various levels of government; coalitions among providers; one stop shopping for services; combining housing and services; train professionals as they are getting their education about disability populations – provide internships in community programs; borrow and

adapt exemplary practices from other disability services

E. What state strategies could help to expand services?

Recommendations related primarily to funding flexibility and expansion:

-More money, less restrictions

-Increase Medi-Cal waivers

-Increase waiver programs for in-home care instead of nursing home care

-Rewrite Medi-Cal waivers to maximize federal dollars that supplement/not -Supplant State money

-Expand Medi-Cal IHSS from federal poverty level plus 230% to the full amount that CMS allows – 3 time federal poverty level

-Rewrite waivers to cover new technology

-Reinvest proceeds from sale of DCs into DD services

-Combine state agencies administratively and fiscally (e.g., Mental Health and Alcohol & Drug)

-Develop universal design concepts for housing

KEY ISSUE III: STRATEGIES TO INTEGRATE OLMSTEAD INTO LOCAL PLANNING EFFORTS

A. Aging:

-In San Francisco, strategic planning is being conducted over 18 months at the Department of Aging and Adult Services through a community public/private partnership and the Living with Dignity Policy Committee to undertake local planning in response to the Olmstead decision.

-Include community-based senior services as part of general land use and community planning

-Develop collaboratives with all key players and providers

B. Disabilities:

-Include people with disabilities in any work group

Have input from people who will be affected whenever plans, regulations and guidelines are developed

C. Housing:

Relax local ordinances that keep people

from living together and sharing assistants

-Develop set asides for accessible housing

-Develop consequences for local entities that do not implement their housing plans (elements)

-Increase SSI/SSPI

-Advocate for very long-term, low or no interest HUD home loans for frail elderly and disabled

D. Transportation:

Develop collaboratives with all key players and providers

E. Other:

Make local governments, service providers, residential providers

and People 1st aware of Olmstead Plan

-Foster coordination among planning, public works and human services departments

-Work with Mental Health Advisory Board to form subcommittees for development of education programs

-County/regional general plans need to account for disability needs during the planning process

FORUM SPONSORS:

Center for Independence of the Disabled, San Mateo

Area Agency on Aging, ILRC, ABIX & TCRC, Santa Maria, September 24, 2002, 5-20 participants (Providers and Advocates), modified public hearing

Living with Dignity Policy Committee, San Francisco, September 19, 2002, 43 (8 consumers, 13 providers, 3 public officials, 19 advocates); public hearing

Area Board 5 on Developmental Disabilities: September 25, Ft. Mason & San Francisco; 50; public hearing (25 consumers/ 10 friends/family/10 providers/5 advocates)

Area Agency on Aging, Merced: September 24, 2002; 29 (25 providers, 2 consumers, 2 friends/family); public hearing

The Access Center: Balboa Park Club

California Assisted Living Association: Sacramento, September 20, 2002, 5 – 20 people; providers-assisted living

California Association of State Hospital Parent Councils for the Retarded (CASHPCR) & co-sponsors: Agnews, Sonoma, Porterville, Fairview and Lanterman Developmental Centers, September 2002; **& Canyon springs Community Facility,** October 2002.

Council on Aging, Silicon Valley, San Jose, September 30, 2002, 46 (consumers, friends/family members, providers, public officials and advocates), public hearing

Community Catalyst, Merced

Independent Living Resource Center, Ventura, October 23, 2002, 10 (1 consumers, 1 friends/family, 3 providers, 5 advocates), roundtable discussion

Tuolumne County Behavioral Health, Sonora, September 23-27, 2002, 47 (21 consumers, 8 friends/family, 3 providers, 15 advocates); individuals came to office, drop-in center or NAMI group or faxed or called in survey over a week's period.

New Start Healthcare Corporation, Northridge, September 20, 2002, 50+ (consumers, friends/family, providers, public officials, advocates); roundtable discussion

LA County Leadership Council of Aging Organizations, October 25, 2002; 5 – 20 (providers, public officials and advocates); group meeting/discussion

Area Board VII, San Jose, November 4, 2002; 21 (18 consumers of long-term care services; 3 Developmental Center staff); Roundtable discussion at People First meeting and individual discussions with residents

PIRS, Auburn

DD Area Board XIII, SD People 1st, SD Regional Center, SD Vendor Coalition; October 24, 2002

California Northeastern Counties Olmstead Coalition, submitted October 10, 2002, representing 17 Aging, Developmental Disability, Caregiver, HSSP, Linkages, Independent Living Services and other disability agencies and coalitions in Butte, Colusa, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama and Trinity counties; October 10, 2002; written communication

Orange County Collaborative, 3 public hearings, San Juan Capistrano, September 23; Santa Ana, September 27; Orange, September 30; 20 to 70 (consumers, friends/family member, providers,

public officials, advocates, government agencies, senior advisory entities, and CA Senior Legislature)

Hillside House, Santa Barbara, October 28, 2002, 26

Brizzolara Apartments, San Luis Obispo, November 12, 2002, 20

Yolo County Long Term Care Coordinating Council, Davis, September, 26, 2002, 29 (3 consumers, 7 friends & family, 4 providers, 3 public officials, 8 advocates, 4 government), roundtable discussion

Area 4 Agency on Aging – Sacramento & Yolo Counties, October 2002, 56 (home-delivered meals clients), survey

Area 4 Agency on Aging – Nevada County, October 2002, surveys distributed at an event in Nevada County sponsored by the Long-Term Care Integration Council, 56 (consumers 65+, with physical, mental & sensory disabilities & caregivers of LTC recipients), roundtable discussion

Californians for Disability Rights, Lucerne Valley Senior Center, 10/16/02; 12 (1 consumer, 2 friends/family members; 2 advocates; 7 at risk

for long term nursing home care); roundtable discussion

Californians for Disability Rights, Ontario, 11/16/02; 1 (3 friends/family members, 1 public official, 6 advocates, 7 at risk -- people 65+, with physical, sensory and developmental disabilities, at risk); roundtable discussion

Madera County Department of Mental Health, October 2, 2002

LA County Leadership Council of Aging Organizations, October 25, 2002, 5-20 (providers, public officials and advocates), group meeting/discussion

Area IX Developmental Disabilities Board, Newbury Park, Simi Valley, October 23 and November 12, 2002, 16 (consumers, friends, family, providers, advocates), roundtable discussion and small groups; material modified to present the key points in a picture/subtitle format to accommodate clients who could not read

OOA/SSA/CalOptima, San Juan Capistrano

Area Board XIII, San Diego Regional Center, San Diego Vendor Coalition, San Diego, October 16,

2002, 5-20 participants (providers, SDRC & ABXIII reps)

PAI & Mental Health Clients for Wellness & Recovery, San Diego, 26 participants (10 consumers – most from a locked facility, 10 providers, 6 advocates); presentation and focus groups